

University of Nebraska - Lincoln

DigitalCommons@University of Nebraska - Lincoln

Uniformed Services University of the Health
Sciences

U.S. Department of Defense

2012

Missed visits and decline in CD4 cell count among HIV-infected patients: a mixed method study

Anna Walburn

Navy and Marine Corps Public Health Center

Susan Swindles

University of Nebraska Medical Center

Christopher Fisher

University of Nebraska Medical Center

Robin High

University of Nebraska Medical Center

K. M. Islam

University of Nebraska Medical Center, kmislam@unmc.edu

Follow this and additional works at: <http://digitalcommons.unl.edu/usuhs>

Walburn, Anna; Swindles, Susan; Fisher, Christopher; High, Robin; and Islam, K. M., "Missed visits and decline in CD4 cell count among HIV-infected patients: a mixed method study" (2012). *Uniformed Services University of the Health Sciences*. 152.
<http://digitalcommons.unl.edu/usuhs/152>

This Article is brought to you for free and open access by the U.S. Department of Defense at DigitalCommons@University of Nebraska - Lincoln. It has been accepted for inclusion in Uniformed Services University of the Health Sciences by an authorized administrator of DigitalCommons@University of Nebraska - Lincoln.



Missed visits and decline in CD4 cell count among HIV-infected patients: a mixed method study

Anna Walburn^a, Susan Swindells^b, Christopher Fisher^c, Robin High^d, K.M. Islam^{e,*}

^a Epi Data Center Department, Navy and Marine Corps Public Health Center, Portsmouth, Virginia, USA

^b Department of Internal Medicine–Infectious Diseases, University of Nebraska Medical Center, Omaha, Nebraska, USA

^c Department of Health Promotion, Social & Behavioral Health, University of Nebraska Medical Center, Omaha, Nebraska, USA

^d Department of Biostatistics, University of Nebraska Medical Center, Omaha, NE 68198–4395, USA

^e Department of Epidemiology, University of Nebraska Medical Center, Omaha, Nebraska, USA

ARTICLE INFO

Article history:

Received 18 January 2012

Received in revised form 8 June 2012

Accepted 15 June 2012

Corresponding Editor: Mark Holodniy, California, USA

Keywords:

HIV infection
Missed visits
CD4 count

SUMMARY

Objective: To determine the impact of missed visits on CD4 cell count with HIV disease in a Midwest clinic.

Methods: This was a mixed method study consisting of a quantitative retrospective cohort study of missed clinic visits among HIV-infected patients, and a qualitative study to collect information on factors impacting appointment attendance. A drop in CD4 cell count greater than 50 cells/mm³ from baseline was the primary outcome variable for the quantitative study. The exposure variable was missed visits. **Results:** Of 77 patients, 16.4% experienced the outcome of interest. Lower visit proportions increased the risk of a CD4 drop (hazard ratio 0.0188, 95% confidence interval 0.001–0.292). For each 10% increase in the missed visit proportion, the risk of a CD4 drop of >50 cells/mm³ from baseline increased by 33%. Qualitative data suggested that stigma, external support, and physician–patient interactions impacted engagement in care.

Conclusion: These results may help providers increase patient motivation and ability to attend clinic appointments.

© 2012 International Society for Infectious Diseases. Published by Elsevier Ltd. All rights reserved.

1. Introduction

Advances in medical care have resulted in an increase in the number of people living with HIV.¹ In turn, medical care for HIV-infected patients must evolve to focus on retaining patients in long-term care. The negative impact of missed visits on subsequent mortality among HIV-infected patients has been examined in several recent studies.^{2,3} For example, it has been found that individuals most at risk of appointment non-adherence come from populations with the highest incidence of HIV – including African American women and people with a low socioeconomic status.^{4–6} This may, in part, contribute to the observation from the Women's Interagency HIV Study of a disproportionate benefit in HIV survival over time following the widespread use of combination antiretroviral therapy, with women experiencing a smaller rate of decline in death rate than men.⁷ In the USA, HIV-infected patients face concurrent problems such as housing instability, lack of medical insurance, and lack of access to medical facilities.⁸ These factors complicate patient appointment adherence.

The existing literature addresses the impact of missed visits on clinical outcomes for HIV-infected patients. Missed visits have been associated with a higher incidence of opportunistic infections, AIDS-defining illness, and death.^{2,3} However, few studies have examined specific barriers to clinic visits that must be identified before effective interventions can be put in place. This study was developed to better understand the reasons for missed visits, in order to develop optimal strategies to improve clinical outcomes. Our goal was to develop opportunities to improve engagement in clinic care from the development of a 'no show' profile specific to the patient load of the University of Nebraska Medical Center HIV Clinic and Nebraska AIDS Project.

The objectives of this study were to determine the relationship between missed outpatient visits and health outcomes related to HIV infection and to identify barriers and facilitators to retention in clinical care. The primary study outcome was a drop in CD4 + T-lymphocyte count greater than 50 cells/mm³ from the baseline CD4 + T-lymphocyte measurement. This objective was supplemented with information from the development of a profile of 'no show' patients in order to better understand the factors affecting patients with high rates of missed visits.

* Corresponding author. Tel.: +1 402 559 8283; fax: +1 402 559 7259.

E-mail address: kmislam@unmc.edu (K.M. Islam).

2. Methods

2.1. Study design

Our study used a mixed methods approach with two parts. Part I, the quantitative portion of the study, was a retrospective cohort study aimed at determining the association between missed outpatient visits and clinical outcomes related to HIV infection. This portion of the study was also used to identify patient characteristics associated with high rates of missed appointments. Part II was a qualitative study aimed at collecting data on barriers and facilitators to appointment attendance by patients at a university medical center HIV clinic and the local AIDS service organization.

For the quantitative portion of the study, all HIV-infected patients presenting at the study clinic between January 1999 and December 2000 were considered for inclusion, and data were collected until December 2008, giving a follow-up period of 9 years. The primary exposure variable was missed visit status, which was recorded as the proportion of visits attended over the total number of visits scheduled during the period of interest. Urgent care and subspecialty visits were excluded. Consistent with other studies, only missed visits where a patient did not call the clinic to cancel or reschedule were included in the missed visit measure.^{9,10} A counting rule was established to identify missed visits. For this study, visits were not included in the missed visit proportion if the patient missed his/her appointment due to hospitalization.

Landmark analysis was used to model the risk of non-adherence. Patients were classified by the number of missed appointments during the landmark period, and then patient characteristics were examined to identify variables significantly related to a higher proportion of missed visits (Figure 1). A stratified compliance method was used to account for the varying levels of illness in patients to adjust for unequal likelihood of missed visits. Sicker patients are more likely to have more appointments and thus more opportunities to miss their appointments. Therefore, the landmark period for patients presenting with baseline CD4 + T-lymphocyte counts of ≤ 100 cells/mm³ was 1 year, as such patients are usually scheduled for more frequent clinic visits. The landmark period for patients presenting with baseline CD4 + T-lymphocyte counts >100 cells/mm³ was 3 years. The proportion of missed appointments was examined, rather than the total number of medical appointments, to reduce potential confounding associated with individual variations in the frequency of scheduled appointments. For the purposes of the analysis, missed visit profiles were divided into

quartiles (i.e., patients with 0–25% visit attendance were assigned to the first quartile, 26–50% visit attendance to the second quartile, etc.).

Patients were followed until December 2008. The outcome of interest was a drop in the CD4 + T-lymphocyte count of at least 50 cells/mm³ from the baseline measurement, as this is generally recognized as a clinically significant decrement and more than the biological variation in the assay. Also a fall in CD4 count is an indication of possible treatment failure.¹¹ For HIV-infected patients receiving antiretroviral therapy, routine laboratory monitoring is associated with improved health and survival compared to clinical monitoring alone.^{12,13} Monitoring patients with CD4 cell counts has been shown to be cost-effective.¹⁴

We invited patients accessing services at a community-based organization (the Nebraska AIDS Project or NAP) and/or the University of Nebraska Medical Center (UNMC) HIV Clinic to take part in the qualitative portion of the study. Potential participants were recruited from those who attended free daily lunches at NAP or those who were regular patients at the UNMC HIV Clinic. Interviews were conducted on site at the clinic.

2.2. Study population and sample size

The initial population for this study consisted of all HIV-infected patients presenting to the study HIV clinic between January 1999 and December 2000.

A total of 215 patients were identified during the defined timeframe. From this sample we eliminated 138 patients due to missing information on clinic visits, resulting in a sample of 77 patients. Many of those excluded were being seen by outside providers but their records were being maintained at the study clinic in order to qualify for federally-funded Ryan White CARE Act services; the study site is the sole site that administers these services for the region. Other patients were excluded due to loss to follow-up, incarceration, or moving away from the area served by the study clinic.

We included patients who had survived at least 6 months after their initial clinic visit, patients over the age of 19 years, and women who were not pregnant during the study period. Patients who died within 6 months of clinic enrollment were excluded because there was insufficient information to calculate a missed visit proportion to define compliance. Pregnant women were excluded because adherence to antiretroviral therapy during pregnancy is higher than for non-pregnant women.¹⁵ Patients under the age of 19 years (the age of majority in Nebraska) were excluded because the main interest of this study was the adult population, and children are not in control of whether or not they

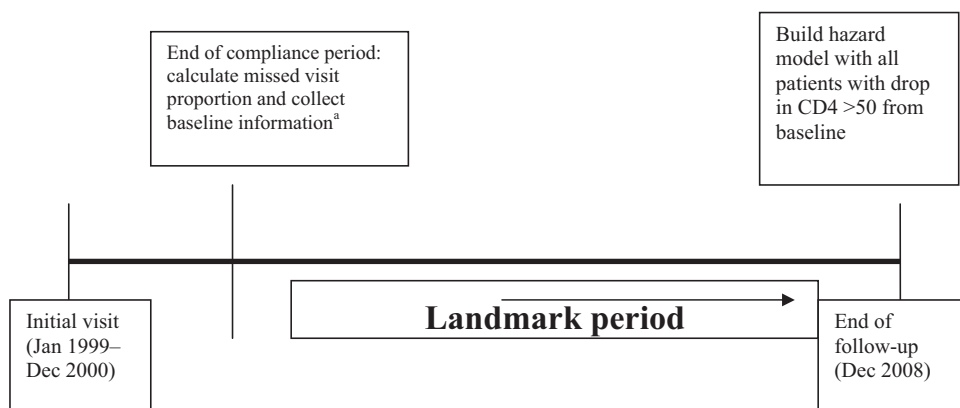


Figure 1. Landmark analysis design (^aEnd of compliance period is 1 year after the first visit for patients with a CD4 count of <100 at their initial visit (landmark group 1), 3 years after the first visit for patients with a CD4 count of >100 at their initial visit (landmark group 2)).

keep a scheduled clinic appointment. Patients who were lost to follow-up during the landmark period were also excluded since they did not have appointment attendance data for the entire exposure period.

Inclusion criteria for the qualitative portion of the study were: being a person living with HIV/AIDS, English-speaking, not pregnant, and over the age of 19 years. Non-probability convenience sampling was used to identify participants for the interview portion of the study. The total number of participants interviewed was determined by theoretical sampling, i.e., conducting interviews until patterns emerged from the data and a saturation of relevant information was reached.¹⁶ Fourteen participants between the ages of 24 and 53 years completed the exploratory semi-structured interviews, including eight women and six men. Eight participants from the AIDS service organization and six participants from the clinic participated.

2.3. Data collection methods and measures

Quantitative measures were collected from the clinic database and patient charts and included: date of first clinic visit, date of death, insurance status, demographic information and patient status (active/inactive), baseline CD4 + T-lymphocyte count, baseline viral load, number of attended visits, number of failed visits, total number of visits, date at which a drop in CD4 + T-lymphocyte count occurred, CD4 + T-lymphocyte count at drop, and final CD4 + T-lymphocyte count.

Data were collected for the qualitative portion of the study by interviewing participants. Each audio-recorded interview lasted between 15 and 30 min and consisted of three main areas of discussion: (1) a rapport-building conversation on the person's identity as a person living with HIV/AIDS, (2) aspects of appointment adherence, including issues with accessing clinic appointments, perceived benefits of care, and difficulties they face in keeping clinic appointments, and (3) social support related to appointment adherence and managing their illness (Appendix 1). All protocols were approved by the Institutional Review Board of the University of Nebraska Medical Center.

2.4. Analytical methods

For the quantitative data, initial descriptive and bivariate statistical analyses were completed to describe study population characteristics and to identify possible relationships between the variables. Next, the data of all patients with both an initial and final CD4 count and landmark visit proportion were fit with a proportional hazard regression model. An alpha level of 0.05 was used for all statistical tests. Data were analyzed using both SPSS and SAS software.

Data were analyzed using a drop in CD4 + T-lymphocyte count >50 cells/mm³ from the baseline CD4 + T-lymphocyte measurement as the outcome (Figure 2).

For the qualitative portion of the study, participant interviews were transcribed verbatim and assigned a pseudonym. A grounded theory approach was used for data collection and analysis.¹⁶ Analysis began by coding words and passages and then collapsing codes into conceptual categories. Coding schemes were developed to identify the emerging theories in the data. A second person, trained in qualitative analysis and not otherwise involved in the project, independently analyzed the data to provide inter-coder reliability and validate the emerging themes to ensure themes were not the sole interpretation of the first author. A process of discussion validated the emerging themes followed, where 100% agreement was reached on the salient themes found in the transcripts.

3. Results

3.1. Quantitative results

There were nearly twice as many men as women in this study; the median age of the subjects was 44.51 years. There were more patients in landmark group 2 (baseline CD4 count >100 cells/mm³) for both men and women. The population was predominantly uninsured, low income, and dependent on federal funding for their HIV care (Table 1).

The demographics available for the initial 215 patients identified did not differ significantly from the demographics of

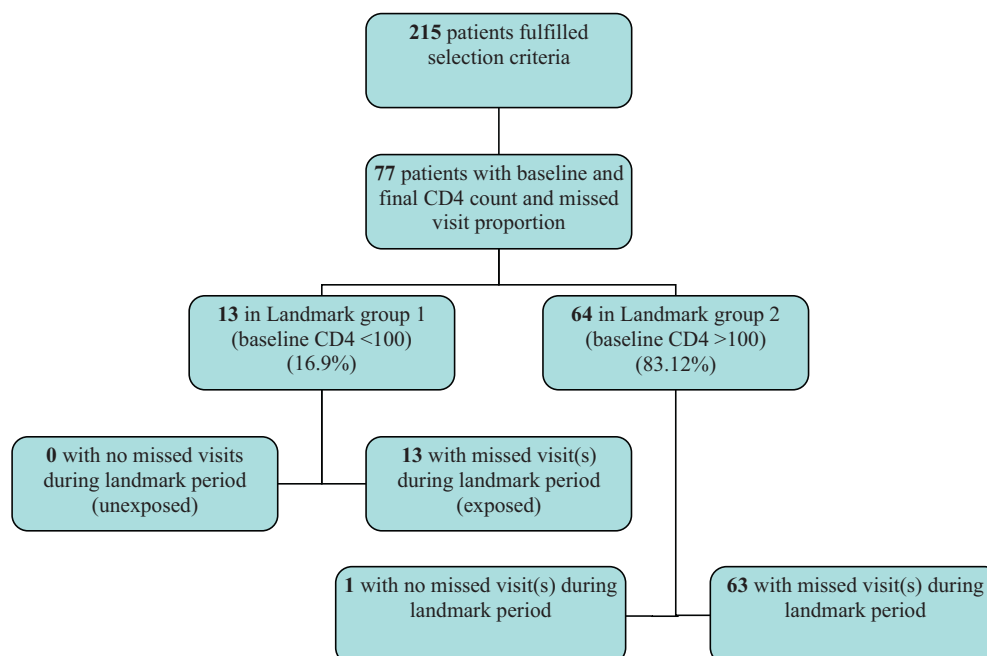


Figure 2. Distribution of study participants.

Table 1
Baseline characteristics of study participants (N = 85)^a

Characteristics	Female (n = 28)	Male (n = 57)
Age (years)		
Mean	43.43	45.58
Range	28–70	27–70
Race		
White	11 (12.9%)	34 (40%)
Black	9 (10.6%)	12 (14.1%)
Other	8 (9.4%)	11 (12.9%)
ADAP		
Yes	18 (21.2%)	35 (41.2%)
No	10 (11.8%)	22 (25.9%)
Baseline CD4 (cells/mm ³)		
Mean	290.89	461.39
Median	234.00	342.00
Range	4–881	16–1428
Landmark group ^b		
Landmark 1 (baseline CD4 <100)	3 (3.5%)	12 (14.1%)
Landmark 2 (baseline CD4 ≥100)	25 (29.4%)	45 (52.9%)
Visit proportion (N = 77) ^a		
0–0.25	0	0
0.26–0.50	3 (3.9%)	6 (7.8%)
0.51–0.75	5 (6.5%)	12 (15.6%)
0.76–1.0	19 (24.7%)	32 (41.6%)

ADAP, AIDS Drug Assistance Program.

^a This table describes the cohort at baseline; eight participants were missing information necessary to calculate the missed visit proportion and were not included in the analysis.^b Statistically significant, $p < 0.05$.

the final subset used for the analysis (data not shown). The final analysis was modeled using data from 77 patients. The majority of patients were in the fourth quartile, meaning they attended 76–100% of their appointments. There were no patients in the first quartile of 0–25% appointment attendance. Analysis of variance (ANOVA) was conducted with each of the covariates to examine the differences between each of the quartiles of landmark visit proportion in the sample. There were statistically significant differences between the quartiles of landmark visit proportion for patients who were recipients of the AIDS Drug Assistance Program (ADAP) ($F = 6.328$, $p = 0.003$). Patients who kept more clinic appointments were more likely to be recipients of ADAP when compared to those with insurance (Table 2).

Table 3 shows the median CD4 counts at baseline for each of the covariates. To examine the differences between median baseline CD4 counts for race, ANOVA was conducted. Mann–Whitney tests for nonparametric statistics were conducted to examine the differences between the other covariates and median baseline

Table 2
Bivariate analysis of landmark visit proportion quartiles (N = 77)

	Q1 (n = 0)	Q2 (n = 9)	Q3 (n = 17)	Q4 (n = 51)
Percent total	0	11.7%	22.1%	66.2%
Age (years), median	N/A	44.0	44.0	45.0
Race				
White	N/A	3 (3.9%)	10 (13.0%)	24 (31.2%)
Black	N/A	5 (6.5%)	5 (6.5%)	11 (14.3%)
Other	N/A	1 (1.3%)	2 (2.6%)	16 (20.8%)
Gender				
Female	N/A	3 (3.9%)	5 (6.5%)	19 (24.7%)
Male	N/A	6 (7.8%)	12 (15.6%)	32 (41.6%)
Insurance status ^a				
ADAP	N/A	6 (7.8%)	5 (6.5%)	38 (49.4%)
Baseline CD4, median	N/A	373.00	249.00	308.00
Landmark group				
Landmark 1	N/A	0	4 (5.2%)	9 (11.7%)
Landmark 2	N/A	9 (11.7%)	13 (16.9%)	42 (54.5%)

N/A, not applicable; ADAP, AIDS Drug Assistance Program.

^a Statistically significant, $p < 0.05$.**Table 3**
Bivariate analysis of CD4 count at baseline

	CD4 count at baseline
Race	
White	313.0
Black	364.0
Other	198.0
Gender ^a	
Female	234.0
Male	342.0
Insurance status	
ADAP	310.0
Landmark group ^a	
Landmark 1	17.0
Landmark 2	340.0

ADAP, AIDS Drug Assistance Program.

^a Statistically significant, $p < 0.05$.

CD4 counts. The effect of gender was significant; CD4 count at baseline was lower for females than males ($t = -2.683$, $p = 0.004$). By nature of the study design, the effect of landmark group was also significant; landmark group 2 had a significantly higher baseline CD4 count than landmark group 1 ($F = 35.822$, $p < 0.001$).

A visual representation of the primary outcome of a drop in CD4 + T-lymphocyte count of >50 cells/mm³ from baseline is provided in Figure 3. Ten patients had the event before the landmark period, so under landmark guidelines they were excluded. This left a total of 67 patients with 11 events.

Final hazard modeling was developed using data from 77 patients; 11 of these patients experienced the event of interest of a drop in CD4 + T-lymphocyte count >50 cells/mm³ from the baseline CD4 + T-lymphocyte measurement. Proportional hazard models were used to estimate the effect of missed visits on the outcome of a drop in CD4 + T-lymphocyte count of >50 cells/mm³ from the baseline. Of the 77 patients used for modeling, 16.4% experienced the outcome of a drop in CD4 count >50 cells/mm³ from baseline. The landmark visit proportion was found to be significantly related to a drop in CD4 count >50 cells/mm³ from baseline ($p = 0.0045$). Lower visit proportions increased the risk of a CD4 drop (hazard ratio 0.0188, 95% confidence interval 0.001–0.292). The calculated hazard ratio of 0.0188 corresponds to a per unit increase in the missed visit proportion. This number can be used to estimate the percent change in risk of the outcome based on a patient's missed visit proportion: for each 10% increase in the missed visit proportion (i.e., the more appointments a patient misses), the risk of CD4 drop of >50 cells/mm³ from baseline increases by 33%. Proportional hazard models were also used to estimate the effect of gender on the outcome of interest; this was not statistically significant ($p = 0.2457$).

3.2. Qualitative results

Interviews with HIV-positive individuals currently receiving medical care illustrated three themes related to appointment adherence. They included the structure of medical care, value of compliance, and motivation.

3.2.1. Structure of medical care

The narratives of this project's participants reflect the importance of continuity of care and satisfaction with their health care providers. Steven, a 53-year-old man recently engaged in care after many years living with HIV, commented on his relationship with the providers:

... when I was in Texas the little bit that I did go [to appointments] you were more like a name and a number there. Here, there's... a personal relationship. They make you feel comfortable.

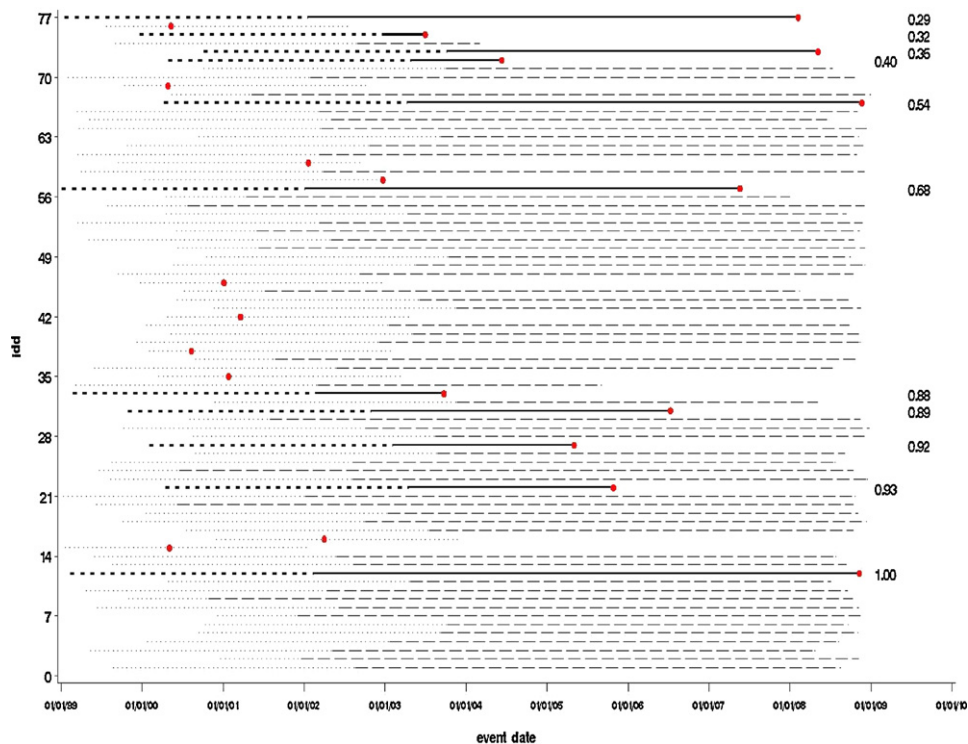


Figure 3. Event date (CD4 drop >50) in relation to landmark visit proportions. Patients who experienced the outcome before the end of the landmark period are represented by a dot only on the timeline. Patients who experienced the outcome after the landmark period have a dashed line from the end of the landmark period to the end of the study. Patients with a CD4 drop greater than 50 from baseline whose event data extend later than the landmark period have a solid line with a dot on the event date.

People who described positive relationships with their providers felt more respected and valued as a participant in their own medical care.

Participants who trusted their physician's ability to treat their illness were more likely to describe themselves as fully in care. This, along with physician–patient communication, was mentioned as an important structure of medical care. Don, a 46-year-old participant engaged in care for over 10 years, gave this account of his initial experiences with staff at the clinic:

When I first came in [to the clinic] I was very skeptical. But the staff, particularly [name deleted], she assured me. She helped me realize...that if I did the right things I could still live a long life. When I first came here I... I looked like walking death. I didn't think I was going to, you know, every day I woke up was a blessing but I didn't think I would make it too long. And, she told me I would get better and sure enough I did.

In contrast, participants who described negative experiences with their health care providers were less likely to seek medical care. Joe, a 42-year-old participant who struggled with medical issues related to treatment at a facility in California, described his challenges:

The doctors told me what I needed to do [for treatment]. When I started the treatment it scared me because my T-cell count was 400 something and it dropped. And it scared me, but they said "Oh, you'll be fine." It's like playing poker. Luckily now I feel fine.

Joe continued on to express feeling a lack of control over his health care decisions and the subsequent interruption in care he experienced. Overall, participants characterized by positive provider–patient relationships and a degree of control over their health care were more likely to identify themselves as fully engaged in care.

3.2.2. Value of compliance

Across the narratives, participants who perceived adherence to appointments as a valuable way to remain healthy while living with HIV were more likely to report not missing scheduled appointments. Many participants feared an interference with their social roles if they were to get sick and identified this as an important reason to remain adherent to all appointments. Natosha, a 41-year-old mother of one, cited her daughter as an important reason to be engaged in care:

... I have to take care of myself. I don't want anything to happen to me. I have a daughter to take care of so I want to live long as much as I can, so I have to follow instructions so I can be able to live long as much as I can and I don't want to have any issues' cause of not coming to my appointments.

Taking care of oneself in order to provide support for one's family was a key theme in the narratives.

In contrast, participants who did not perceive themselves as vulnerable tended to find continued appointment adherence less important. Sarah, a 34-year-old recovering alcoholic/addict, did not identify HIV as a significant threat to her health:

I don't know what being HIV-positive means to me. Just that I have this, I guess, quote unquote disease that I just can't get rid of. I haven't really made any changes due to being HIV-positive. I've done all my lifestyle changes because of being a recovering addict/alcoholic and that's what's more important to me because it doesn't matter whether I'm sick or not the drugs and alcohol are going to take my life away if I don't stop and it'd be a lot sooner than the HIV.

The degree of illness participants experienced emerged as a component of compliance value. Participants who became ill as a result of their lack of appointment attendance often reported

becoming fully engaged in their care following the illness. Steven discussed his experience with dropping out of care:

When I was diagnosed my T-cell count was up real high and they told me they didn't recommend giving me any medications...and then I just kind of took off. 'Pry sounds crazy but I just went away and just quit seeing the doctor. I am now, I got back into treatment after getting Hep C and losing a bunch of weight...I can just tell my body doesn't feel the same way...

Those participants who categorically expressed other priorities or a belief that they were 'too healthy' were more likely to report repeatedly missing clinic visits.

3.2.3. Motivations

Participant narratives identified both positive and negative external influences in their HIV care. Stable, in-care participants acknowledged the importance of support from family, friends, partners, and other people living with HIV. Spirituality was also singled out as a means of support for staying in care. In contrast, narratives among participants who reported missing clinic appointments reflected negative influences from stigma, loneliness, and unsupportive family environments. Sarah discussed the problems she had with her family:

It's funny, my friend had it [HIV] and none of my friends or family had issues with it, they were like "Oh, ok" but then when they heard that I was sick, and not one of them have asked me directly, and they're just like "Ugh" and if they're drinking water or whatever, they'll make comments and snide remarks about being HIV-positive.

Fear of disclosure was reported across the narratives. The degree to which a participant feared others finding out about his/her HIV status was often indicative of that person's engagement in care. Dan, a 24-year-old patient who was diagnosed with HIV 3 years ago, declared that he worried "all day every day" about people finding out. This apprehension affected Dan's physical health as well as his ability to seek out support and other services. He explained:

It's like once I leave this clinic everything I just talked about stays in and I hate to take it outside of the clinic with me...I've actually looked very closely at [local ASO] into what it's about, about joining. BUT there's a lot of people that hangs around [local ASO] that I may know...That's probably the biggest thing keeping me away is just knowing you know, is there people there. I swear, you don't even know, before I even walk into this clinic I peek in the door, I won't come in if there's someone I know...my blood pressure tends to rise on the day of my appointments, kinda being horrified that I'll walk into the lobby area or the waiting room into a room full of people that I may know.

The narratives indicated that positive external support provided ongoing motivation to take care of one's health, while disincentives like stigma and fear of disclosure inhibited appointment adherence.

Self-reliance was categorically identified by nine participants as a motivation for staying healthy and remaining in care. In contrast, participants who seemed apathetic about their HIV diagnosis often reported missing visits because they were busy, 'just lazy', or they forgot about the appointment. Antonio, 41 years old, reported being "very depressed" in the 2 weeks after his diagnosis, but quickly turned things around; he stated:

After those two weeks I take control of everything. Just by myself. I just start to think about what I was gonna do. I got out

of that depression, I started to get a little bit more concerned about my health in general, not just about HIV. And actually...I don't regret, and I think I am having better lifestyle because I focus more on taking care. It is even better.

Participants whose narratives identified their HIV diagnosis as a turning point for positive life changes were more likely to report being adherent with scheduled clinic visits. Charles, a man in his mid-fifties who reportedly "never misses an appointment", talked about the changes his HIV diagnosis made in his life:

I think that I have learned a lot of positive things from it [the HIV diagnosis]. I've learned how to be patient. I've learned how to be tolerant. You learn, kinda see how some people perceive you and stuff like that, and being tolerant you know what you're going through so you know what other people are probably going through too, so you're more tolerant to what your surroundings are, people around you.

Maintaining positive relationships with friends, family, and partners and continuing to be optimistic about life serves as motivation for patients to make their clinic appointments and be proactive in their medical care. In contrast, participants who did not mention any external support in their HIV experience or who identified negative influences like stigma or fear of disclosure were less likely to report always adhering to clinic appointments.

4. Discussion

While the majority of patients included in the study attended between 76% and 100% of their scheduled appointments, we observed skewed appointment adherence. Missed visits are not likely to be causally responsible for the higher risk of a CD4 drop from baseline, but are likely to be a risk factor for negative outcome for patients living with HIV. Our study data suggest that for a 10% increase in the missed visit proportion (i.e., the more appointments a patient misses), the risk of a CD4 drop of >50 cells/mm³ from baseline increases by 33%. These findings confirm those of other studies.¹⁰

CD4 cell counts can be an early predictor of treatment failure during antiretroviral therapy, manifested either by a sustained decrease or failure to increase over time on treatment.¹⁷ Reasons for missed visits are complex.¹⁸ The qualitative interview with the patients highlighted a few factors that can reduce the missed visit proportion for long-term care of patients living with HIV. It is important to establish a positive physician–patient relationship and to understand patient's pressing issues such as stigma and the need for external support; this could improve adherence to scheduled visits for long-term care. Factors established from the qualitative portion of the study can be considered as a 'no show profile' for missed visits, as the qualitative sample was a subset of the study population. These factors are negative relationships with health care providers, less control over care, perceived 'too healthy', lack of external support, and experiences of negative influences, such as stigma and fear of disclosure of HIV status.

Limitations to this study include the small sample size and retrospective nature of the quantitative analysis. However, the retrospective nature also provided strengths by allowing for inspection of data over an 8-year period. Unknown confounders and missing data may distort associations and complicate interpretations. Possible confounders in this study include undocumented substance abuse and mental illness.

The qualitative portion of the study provides fundamental, theoretically grounded attitudes and perceptions related to outpatient appointment adherence for people living with HIV.

A small, diverse group of people living with HIV recounted stories about their identities as HIV-infected individuals, their perceived barriers and facilitators to appointment adherence, and their experiences with the health care system. These narratives highlight the important roles that stigma, external support, and physician–patient interactions play in understanding long-term engagement in care.

A web of determinants impact a patient's ability and motivation to attend scheduled appointments. The practice of clinical medicine at an individual level is critical to ensure that patients remain healthy while living with HIV. In addition to this, however, providers must bridge the gap between knowledge of a patient's physical condition and the outside factors that affect his/her disease. The themes identified through interview analysis may be useful for health care providers in shaping an ecological method of HIV care. Patient interviews identified several aspects of the care they receive at the UNMC clinic as beneficial. The friendly atmosphere at the clinic coupled with the encouragement of clinic staff were mentioned numerous times and should be considered crucial to engaging patients in care. Spending time with patients to identify pressing needs may help ameliorate the disproportionate impact that socioeconomic factors have on HIV patients. By helping people living with HIV identify solid support systems and needs outside of HIV-related care, providers at the UNMC clinic may increase their patients' motivation and ability to attend clinic appointments.

In conclusion, many studies of HIV patient care have dealt primarily with superficial demographic and background variables. This study went beyond the one-dimensional, clinical view of HIV to identify factors that inhibit engagement in HIV care. Results from this study reflect the need to take an ecological approach to HIV care. By working with patients to treat not only their clinical symptoms, but also to address outside issues like stigma, social support, and other pressing needs, providers may be able to improve both individual health and population outcomes.

Conflict of interest: No conflict of interest to declare.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.ijid.2012.06.004>.

References

1. Palella Jr FJ, Delaney KM, Moorman AC, Loveless MO, Fuhrer J, Satten GA, et al. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *N Engl J Med* 1998;**338**:853–60.
2. Giordano TP, Gifford AL, White Jr AC, Suarez-Almazor ME, Rabeneck L, Hartman C, et al. Retention in care: a challenge to survival with HIV infection. *Clin Infect Dis* 2007;**44**:1493–9.
3. Mugavero MJ, Lin HY, Allison JJ, Willig JH, Chang PW, Marler M, et al. Failure to establish HIV care: characterizing the “no show” phenomenon. *Clin Infect Dis* 2007;**45**:127–30.
4. Bunting SM, Bevier DJ, Baker SK. Poor women living with HIV: self-identified needs. *J Community Health Nurs* 1999;**16**:41–52.
5. Catz SL, McClure JB, Jones GN, Brantley PJ. Predictors of outpatient medical appointment attendance among persons with HIV. *AIDS Care* 1999;**11**:361–73.
6. Sherer R, Stieglitz K, Narra J, Jasek J, Green L, Moore B, et al. HIV multidisciplinary teams work: support services improve access to and retention in HIV primary care. *AIDS Care* 2002;**14**(Suppl 1):S31–44.
7. French AL, Gawel SH, Hershow R, Benning L, Hessol NA, Levine AM, et al. Trends in mortality and causes of death among women with HIV in the United States: a 10-year study. *J Acquir Immune Defic Syndr* 2009;**51**:399–406.
8. Colbert A. An examination of the relationships among gender, health status, social support, and HIV-related stigma. *J Assoc Nurses AIDS Care* 2010;**21**:302–13.
9. Israelski D, Gore-Felton C, Power R, Wood MJ, Koopman C. Sociodemographic characteristics associated with medical appointment adherence among HIV-seropositive patients seeking treatment in a county outpatient facility. *Prev Med* 2001;**33**:470–5.
10. Mugavero MJ, Lin HY, Willig JH, Westfall AO, Ulett KB, Routman JS, et al. Missed visits and mortality among patients establishing initial outpatient HIV treatment. *Clin Infect Dis* 2009;**48**:248–56.
11. Williams PL, Currier JS, Swindells S. Joint effects of HIV-1 RNA levels and CD4 lymphocyte cells on the risk of specific opportunistic infections. *AIDS* 1999;**13**:1035–44.
12. Swindells S, Evans S, Zackin R, Goldman M, Haubrich R, Filler SG, et al., AIDS Clinical Trial Group 722 Study Team. Predictive value of HIV-1 viral load on risk for opportunistic infection. *J Acquir Immune Defic Syndr* 2002;**30**:154–8.
13. Mermin J, Ekwaru JP, Were W, Degerman R, Bunnell R, Kaharuzza F, et al. Utility of routine viral load, CD4 cell count, and clinical monitoring among adults with HIV receiving antiretroviral therapy in Uganda: randomised trial. *BMJ* 2011;**343**:d6792.
14. Kahn JG, Marseille E, Moore D, Bunnell R, Were W, Degerman R, et al. CD4 cell count and viral load monitoring in patients undergoing antiretroviral therapy in Uganda: cost effectiveness study. *BMJ* 2011;**343**:d6884.
15. Rodrigues Vaz MJ, Oliveira Barros SM, Palacios R, Senise JF, Lunardi L, Amed AM, et al. HIV-infected pregnant women have greater adherence with antiretroviral drugs than non-pregnant women. *Int J STD AIDS* 2007;**18**:28–32.
16. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London, UK: Sage Publications; 2006.
17. Badri M. Utility of CD4 cell counts for early prediction of virological failure during antiretroviral therapy in a resource-limited setting. *BMC Infect Dis* 2008;**8**:89.
18. Arici C, Ripamonti D, Maggiolo F, Rizzi M, Finazzi MG, Pezzotti P, et al. Factors associated with the failure of HIV-positive persons to return for scheduled medical visits. *HIV Clin Trials* 2002;**3**:52–7.